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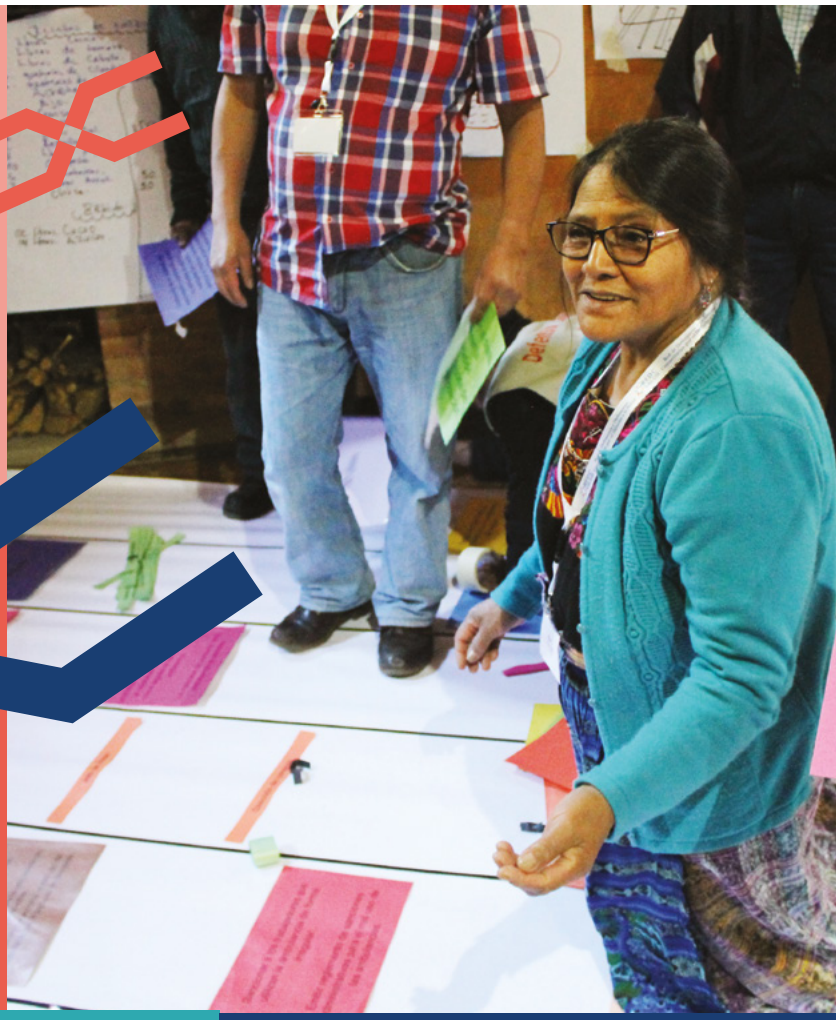
What does it mean to take a "Leave No One Behind" approach to Community Engagement and Involvement in Global Health Research?

Erica Nelson, Institute of Development Studies, United Kingdom
Sana Contractor, Independent Consultant and Affiliate, India, COPASAH
Rebecca Racheal Apolot, Makerere University School of Public Health, Uganda
Sabrina Rasheed, iccdr'b, Bangladesh
Walter Flores, Centre for the Study of Equity and Governance in Health Systems, Guatemala



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For more information please contact NIHR CCF Community Engagement and Involvement Team: email: ccfcei@nihr.ac.uk

Front cover image:
Annual review meeting in Sacatepequez Province, Guatemala

Introduction

In this last publication for the 2020-2021 IDS/NIHR Community Engagement and Involvement learning series, we discuss what it means to take a CEI approach that prioritises 'leaving no one behind'[1]. As with other resources developed in this series, this text builds on a series of conversations between the lead author and a group of Low and Middle Income Country-based experts who bring a depth of experience and critical insights to current debates on what constitutes CEI good practice. The intention of the series as a whole has been to encourage funding applicants to ask themselves hard questions about inclusivity, power and bias as they embark on the initial thinking and design of the CEI component of a given proposal. Here we take on the existing rhetoric of 'leaving no one behind' in global health research and how it is sometimes misinterpreted as a demographic tick-box exercise. We ask instead: what is getting left behind in global health research, why is 'leaving behind' a phenomena of contemporary development and global health processes, and how can these issues be addressed through a CEI approach, albeit with limitations?

For NIHR's Global Health Research portfolio, meaningful and inclusive CEI is a requirement of all applications for funding, and the organisation's strategic approach to CEI is shaped by the pledge to 'leave no one behind' as articulated in the United Nation's Sustainable Development Goals (SDGs) [2]. What this means in practice is that NIHR-funded global health researchers and stakeholders are expected to take into account experiences of marginalisation, discrimination and inequality where they work, and in how they work, and to then identify measures to address these challenges. There are a wide range of tools and guidelines developed to help governments and stakeholders to take seriously the issue of 'leaving no one behind' when it comes to health systems planning and health services accessibility and quality[3]. Here we reflect on what CEI practitioners have learned 'by doing' in terms of working with groups and individuals who experience multiple and intersecting forms of marginalisation and vulnerability and seeking to engage them meaningfully in processes of research[4-6].

"The people you work with are your most important capital. You should not think for people, you need to hear how they think and you need to listen. Your life as a researcher will get much easier if you listen…when you design and do everything with the community, instead of imposing your ideas on them, then the process will work much better…what I have learned is that when you are working with the people you think you are "technically supporting" they are actually technically supporting you!"

Rebecca Racheal Apolot, MUSPH

What is often left behind in global health research?

A common understanding of the SDG's 'leaving no one behind' agenda centres on addressing the needs of individuals and groups with shared characteristics (ethnicity, race, gender, religion, socio-economic status, geographic location and so forth) that render them more vulnerable to extreme poverty, ill-health and social exclusion[7]. Over the past nearly two decades, a social determinants approach to understanding the drivers of health inequities has shed further light on the systems and structures of power that shape these dynamics[8-9]. While there has been tremendous advancements in understandings of the drivers of health inequities, public health researchers have still struggled to meaningfully incorporate the diverse perspectives of those who experience these inequities in their day-to-day lives. What is therefore often left behind in global health research is this much broader landscape of valuable knowledge, which includes indigenous, non-'Western', culturally-specific and experiential forms of knowledge[10-11].

Guided by a commitment to 'leaving no one behind' that extends beyond the rhetoric of the SDGs, the Centre for the Study of Equity and Governance in Health Systems (CEGSS) has worked to expand what it means to do research with marginalised and vulnerable populations. There are many lessons to be drawn from this work, but for the purposes of this guide we mention two:

Firstly, the role of grassroots organisations who have established relationships of trust with marginalised and vulnerable populations is absolutely crucial in the context of building inclusion into global health research processes. Their involvement should be considered at all stages of research, e.g. in how research agendas are formed, how research projects are designed and implemented, in analysis processes and in the translation of research into something that local communities deem as both valuable and needed. Grassroots organisations that are particularly skilled at integrating diverse forms of knowledge in their own practices are best positioned to help broaden the scope of whose knowledge counts and what kinds of knowledge count within a given research programme[12].

Annual review meeting in Sacatepequez Province, Guatemala © *CEGSS, Guatemala.*

The second important lesson for CEGSS has been that empowering meaningful inclusion of marginalised groups within research over time as an overarching agenda, sometimes demands stepping back from a focus on the research to instead put effort towards meeting the urgent needs of these groups, which might include issues related to personal safety, government reprisals, emergency housing and issues of food security[13]. In practice, this has meant that over time CEGSS has altered the makeup of its core team and have added staff with legal expertise, in recognition of the particular needs of internally displaced indigenous groups and those targeted by the state. This is not a required element of Community Engagement and Involvement, per se, but instead it is a reflection on what it means to do CEI ethically, paying with close attention to the lived experiences and needs of vulnerable people[14]. In this sense, through doing CEI a research team or group might realise that they need to seek out resources beyond the remit of their time-bound project and commit to longer-term processes of change in order to achieve ethically responsible forms of inclusivity in research.

"Leaving no one behind" is generally used as a frame for development aid and refers to marginalised people, but when we are trying to apply this idea to research – when research is about knowledge production – we need to talk about what is being left behind. What is being left behind is indigenous knowledge, indigenous methods, and also the values and the concerns of people that actively produce knowledge but who don't fit into the model of western academia. We are concerned about who is being left behind but we are ignoring what is being left behind."

Walter Flores, CEGSS

Why are people being left behind?

Leaving behind – whether in reference to certain populations or alternative forms of knowledge – is the result of historical processes of discrimination, bias and exclusion[15]. This brief is not the place to unpack the complexity of this topic as it relates to health systems or health research, as the specific forms of inequity will vary widely across contexts. Instead, we suggest that all members of a given research collaboration should take seriously the ways in which unequal relationships of power shape their work, their team structures, their disciplinary biases and their relationships with diverse communities[16]. It is not possible to sidestep the political nature of doing global health work, but what CEI brings to the table is an opportunity to better understand these dynamics as they play out in particular places and at particular times, how they influence health in the broadest sense of the term, and what levers of change can be acted on[17].

> *The idea of "leaving no one behind" is meant to represent equity; it is an acknowledgment that the benefits of development processes have not accrued to the people who need it most. But it is not so much about who is left behind but it is about why people are left behind. Oftentimes, in order to reach out to the who, we end up making more aggressive our existing efforts to improve access to health services, but examining the why might show us a different way to address inequities in health care. The value of "leaving no one behind" as a slogan, therefore, is most powerful when it forces us to examine these underlying causes.*
>
> **Sana Contractor,** COPASAH

How can these issues be addressed via Community Engagement and Involvement and what are the limitations?

Now to some thoughts on how to address the question of "leaving no one behind" within the context of Community Engagement and Involvement work. One of the greatest challenges of CEI in global health research is the tension that exists between capturing the perspectives of those most vulnerable and marginalised within a given group, while at the same time achieving sufficient consensus on research processes and outcomes at community level in order to effectively collaborate[18-19]. To repeat an often stated phrase from this learning programme, there is no "one way" to do CEI, and subsequently there is no "one way" to navigate this tricky balance between collaboration/consensus and challenging the status quo/dissent.

Furthermore, it is important to remember that not everyone wants to join in the processes of development or global health such as these fields are currently structured. To the contrary, there have long been attempts to push forward alternative approaches to achieving healthy societies and communities that require different forms of collaboration and challenge existing hierarchies of expertise in the medical sciences[20]. In a pragmatic sense, there are ways to design CEI to anticipate the range of ideas and perspectives on a given set of research questions that might emerge at local level. Some forms of CEI practice might go beyond what public health researchers are trained to do, and may therefore require additional input and capacity-buidling assistance from organisations and individuals with experience in participatory methods and mutual learning approaches. In this sense, doing good listening in CEI means being open minded enough to having one's own biases and expert knowledge challenged, and the willingness to be adaptive and open to change in response. The shared goal of "leaving no one behind" has the potential to be more than an empty slogan if the global health research community takes seriously the complexity of what this means in practice and takes responsibility for meeting the challenges of meaningful inclusivity in their work.

> *For researchers it is very easy to think that we know what is going on, reading up on all this literature from all over the place, and theories that drive change, so we might have a structure in our minds about what is happening… but there is a place for everyone in the research process and it is important to be sympathetic to that, even while you are pushing for universal inclusion. This has to be a respectful push, though, because we are pushing against the existing structures [of power] within the community.*
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> **Sabrina Rasheed**, iccdr'b

PODCAST

These issues are explored in greater depth in a recent NIHR podcast.
To hear us talk together about what it means to "leave no one behind" in practice in the context of CEI in global health research, **click here.**

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Author info:

Erica Nelson works in a range of overlapping fields that include health policy and systems research, social accountability initiatives, the history of international public health and community engagement and involvement in global health research. She is based at the Institute of Development Studies.

Rebecca Racheal Apolot is a research fellow in the department of health policy, planning and management of Makerere University School of Public health in Uganda whose recent work has included contributions to social accountability and intersectionality focussed research as part of the Future Health Systems(FHS) and Research in Gender and Ethics (RINGS) consortia.

Sabrina Rasheed is an associate scientist at iccdr'b in Bangladesh and adjunct professor at BRAC, whose multidisciplinary work has focused on health systems strengthening, health equity and maternal and child nutrition amongst other topics.

Sana Contractor is a public health researcher and health rights advocate, affiliated with the COPASAH network (Community of Practitioners on Accountability and Social Action in Health). Her particular area of focus is sexual and reproductive health and rights.

Walter Flores is the executive director of the Centre for the Study of Equity and Governance in Health Systems in Guatemala, as well as a global convenor of the COPASAH network. He has over 25 years plus experience working on issues of indigenous health rights and community participation in public health.